

Welcome to Patient and Public Involvement (PPI) at the Centre for Academic Primary Care, University of Bristol

'Together we can make a difference'

Thank you for your interest in being a public contributor to our research!

As a public contributor, your **opinion and your experience** really matter.



Primary care is **healthcare in the community** - everything from GPs to pharmacists, opticians, and dentists. At the Centre for Academic Primary Care (CAPC), we do research that aims to **make primary care better for everyone**. Since our goal is improving care for everyone, it's best that **everyone** is involved.

Your views could **guide** research, **influence** future treatments and **improve** services for patients and the public.

What can you do as a public contributor?

- Share your experiences of primary care, an illness or health condition – which either affects you or someone you care for
- Tell us how you and the people you know feel about a health issue
- Give feedback to researchers about their ideas
- Suggest new research topics
- Help design projects that are most relevant
- Advise on the wording and images used in leaflets for people taking part in research
- Join a research management or advisory group
- Help interpret research results
- Make sure our research reports are easy to read by different audiences
- Help spread the word about our research results.



Why be a public contributor?

Some of our other public contributors tell us:

- 'We need to have a say in the research that affects us'
- 'I wanted to turn a negative experience into something positive'
- 'We all pay for healthcare through tax so we should all have say in how it works'
- 'We told the researchers what we thought would work in the real world'

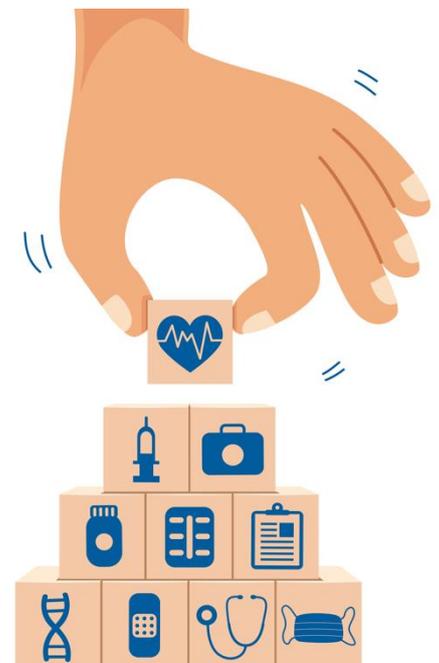
Who can get involved?

Anyone of any age with an interest in healthcare research can join our panel of people willing to help with Patient & Public Involvement (PPI) in research. You don't need to have done anything like this before, and you **don't need qualifications** to get involved. PPI works best with a range of individuals and experiences. We want to hear from **everyone**, regardless of age, background, religion or culture. Any training needed will be given.

What research can I get involved in?

At CAPC, we carry out research in many areas, including:

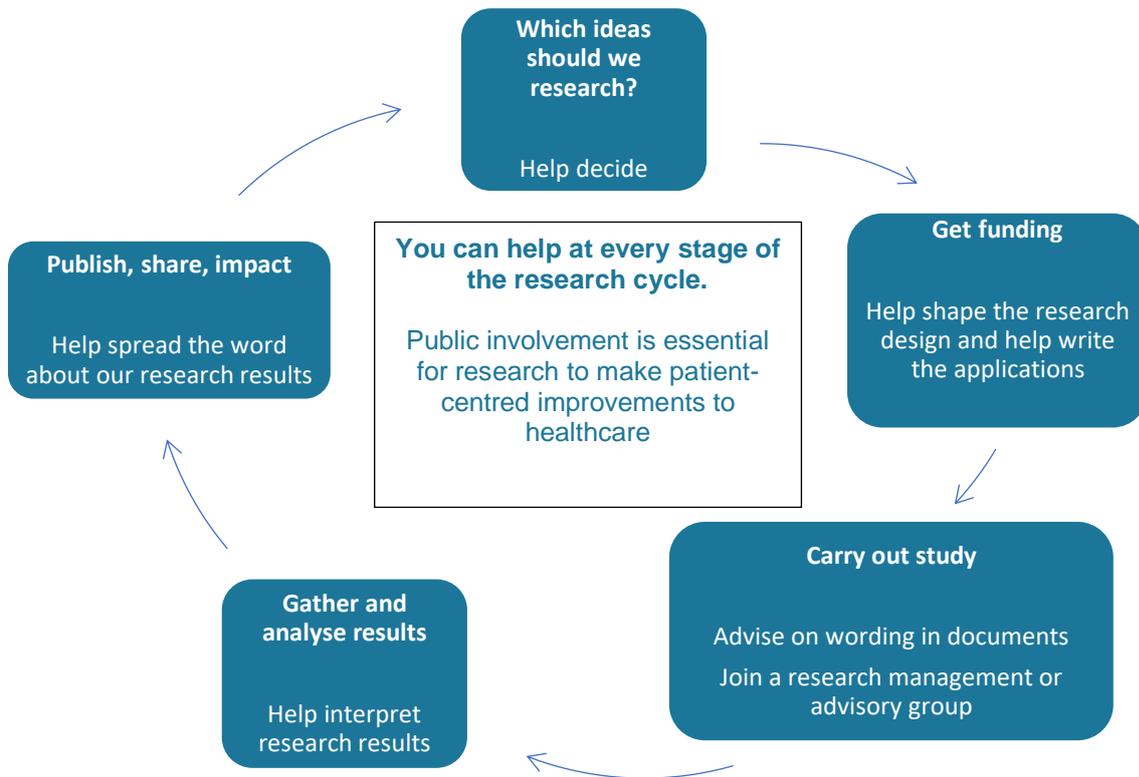
- Finding out what causes health problems in later life
- Helping people with long-term health conditions (like heart disease, mental health and dementia) to keep well for longer and improve their quality of life
- Help patients take the right medication for their condition, and find ways to improve medication management for those with multiple conditions
- Finding better treatments for common problems such as infections (like coughs and colds), eczema, shingles and musculoskeletal problems
- Building relationships to support users of primary health care, including from under-represented communities
- Developing new ways of providing better health care
- Improving the healthcare response to domestic violence and abuse, so that professionals can best support survivors, their children, and those providing informal support.



Gene, Professor of Primary Care: 'We were aware that we had focused our research on the needs of adult survivors of domestic abuse. Our PPI groups made it clear that this was a serious shortcoming and we urgently needed to look at the impact of domestic violence on children. You could do studies on a dozen things... they gave us the reasons to run with this one.'



Different stages, different PPI roles



Public contributors can be involved in some or all stages of research, from initial ideas and helping to **choose, design** and **shape** the project, to making sure results are widely shared. Planning in research is **really important** to make sure we have the **right resources to reach different groups of people**. By asking questions and sharing information public contributors improve research:

- *Have you thought about...?*
- *Don't you think we should tell...?*
- *More people will come if you are located at...*
- *More people will look at the information if....*

Public contributors ask the difficult questions that can help make healthcare work for everyone.

(Barnaby, public contributor) ...' I really enjoy being a PPI contributor. I have learnt so much about research, met great people from all walks of life and been involved in interesting projects. I really felt listened to and pleased that my views have helped shape the research projects. It is rewarding to know that my experiences can help change treatments and as a student the extra money and skills for my CV are a bonus.'





We may ask you to attend meetings, which can be large or small depending on the project. You decide if you want to be involved and you can stop anytime you want to.

When we apply for funding, we will ask what you think of the research idea and the plans for carrying it out. We might also ask you to check if the research application is easy to read. If the project is funded, you could be asked to join a Patient Advisory Group to keep track of how a study is going. Some public contributors also join management and steering groups.

Our projects can last from a few months to several years, but you do not have to be involved for the whole of that time.

(Cindy, senior researcher): 'Having initially been sceptical about PPI, it is now the aspect of health research I most enjoy. PPI contributors' enthusiasm, commitment, insight and surprising perspectives make health research relevant and exciting. They are a crucial part of the team and it's great to have their support and active involvement in the research'.

Researchers need to hear your views and will give you information about their projects before any meetings. They will ask you what you think about their ideas and plans. **Your views are valuable** because you may have ideas and suggestions that our researchers have not thought of. If you feel you need help to speak up in a meeting, please let us know.

Help with involvement

Julie and Victoria, the CAPC PPI coordinators, are there to arrange everything and help in any way they can. Once a project is underway, a member of the research team will usually be on call as well. We can also offer training in different skills, for example how to review documents.



Where?

Meetings are held either using Zoom (or other video meeting app), at the University of Bristol (travel costs are paid) or sometimes in a community location if that is better for you.

Payment

CAPC PPI contributors are paid up to £25 per hour depending on what they are doing, plus expenses. Payments may be by bank transfer, or shopping vouchers, and contributors are responsible for paying their own tax (for further advice, contact the Benefits Advice Service, via the NIHR Centre for Engagement and Dissemination by emailing ced@nihr.ac.uk).

How much time does it take?

The time needed varies from project to project. Some research teams have public advisory groups which support more than one project. These usually meet every 3 months and meetings last 1-2 hours, and there may be additional paperwork to do in between. You would only be involved as much as you can manage and can stop whenever you want.

Want to get involved?

Contact the CAPC PPI&E coordinators, Victoria Wilson and Julie Clayton, by:

- Email capc-ppi@bristol.ac.uk
- Telephone 0117 331 4555
- Electronic sign-up form at the following weblink: [CAPC Patient/Public Involvement in research panel](https://forms.office.com/r/cmpYJsnJHB) (<https://forms.office.com/r/cmpYJsnJHB>).

Diana, public contributor: 'I still have my condition, but my experiences and other people's experiences can help to change things. I know what we do makes a difference, maybe not to my health, but to someone else's, to future generations. To be able to be part of that journey by being involved is an amazing thing to do.'

CAPC researcher: 'It was vital that you had a group of people who could give you a wide cross section of views and experiences on how [they] have been treated with regard to multiple health issues in the real world to keep you grounded'.

Louise, public contributor: 'I think that the public needs to have a voice in the research that's actually meant to be benefiting them'.

With special thanks to:

Public contributors Tom Yardley, Christina Stokes and Louise Ting, as well as Sonia Newman and colleagues at the University of Southampton Primary Care Research Centre.



Further PPI information

Here are weblinks to some short videos and other sources which explain more about getting involved in research.

CAPC PPI animation: <https://www.youtube.com/watch?v=avHdkhIJhy4>

Other animations explaining about PPI in health research

<https://www.youtube.com/watch?v=TFf3HaaSI34>

<https://www.youtube.com/watch?v=PCz7dtZ4YiU>

<https://www.youtube.com/watch?v=srSSsZUbarQ>

[CAPC research](#) – find out more about the research being carried out in CAPC, University of Bristol

[Healthtalk](#) – a collection of people’s experiences of health conditions and their involvement in research

[NIHR Centre for Engagement and Dissemination](#) – honorarium for public contributors

[NIHR Jargon buster](#) – definitions of some of the terms commonly used in research – we also have a version tailored to CAPC research, as well as a list of acronyms, so do ask for a copy!

[NIHR Learning for Involvement](#) – an interactive course for new and experienced reviewers of health and social care research, produced by public reviewers and PPI professionals

[NIHR PPI information](#) – explaining more about what it means to be a PPI contributor to research, including a free training course

[NIHR Public Information pack](#) and [supplement](#) – guides written for patients, carers and members of the public who are interested in getting involved in health or social care research

[NIHR School for Primary Care Research](#) – resources for public contributors

[NIHR UK standards for Public Involvement](#) – a framework for what ‘good’ public involvement in research looks like

[People in Health West of England](#) – an organisation that promotes public involvement amongst professionals and members of the public through news and providing training and advertising PPI opportunities, PPI events

[People in Research](#) – a matchmaking service for researchers to find public contributors and public contributors to find projects that may interest them

